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# Improving Health Care Communication for Persons with Mental Retardation

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## Synopsis .....

*There has been little effort directed at training health care professionals in behaviors and attitudes that are effective in communicating with persons with mental retardation. Such training would be beneficial not only to assist those with congenital*

*cognitive deficits but for those with acquired central nervous system conditions as well, for example, dementia. Persons with mental retardation are living in community settings in greater numbers and increasingly participating in vocational, residential, and health care programs. Yet, most health care professionals are not routinely offered an opportunity to gain experience interacting with people who have limited ability to express and understand health care information.*

*An education program was focused on health care professionals' use of basic communication skills when providing health information to an adult who is mentally retarded. A self-study instructional text and a 20-minute companion video provided methods of communicating with a patient with mental retardation in medical and dental care settings. Resident physicians, medical students, nurses, and nursing assistants improved their communication skills, knew more about mental retardation, and were more proactive in health care interviews following training.*

*Health care training needs to incorporate educational opportunities focusing on skills to assist special populations. Brief, structured, and interactive skill training in communication offered early in the health care professional's career has positive benefits for the recipient and the provider.*

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**C**HANGES IN ethical and legal standards of care have expanded the rights of persons with mental retardation to be informed about and have input into their health care decisions. Open and interactive communication between the health care provider and the patient with mental retardation demonstrates respect for the patient's self-determination and fosters mutual cooperation (1).

Health care providers need to adapt information to the needs of the person with mental retardation to facilitate this process (2). The number of persons who are identified as having mental retardation is growing due to increased longevity; most of those surviving into their senior years (55 and older) have a mild degree of impairment (3). Persons with mental retardation, especially the milder forms, are increasingly taking part in vocational, residential, and health care programs along with their nondisabled peers (4). Yet, most health care professionals

are not routinely offered an opportunity to gain experience interacting with people who have a limited ability to express and understand health care information.

A review of the current literature demonstrates that health care professionals in training need to be routinely exposed to educational information, role models, skill training, and clinical experiences which promote communication with patients (5). Professionals would benefit by learning how to tailor their communications specifically to meet the needs of persons with disabilities (6). Otherwise misinformation, myths, selective experiences, and situational factors (for example, the content of the communication) are likely to guide communications.

Persons with mental retardation are able to participate actively in their own health care; however, some persons with mental retardation require

*'The effectiveness of the educational materials on improving communication skills was not different for health care professionals with advanced educational degrees than for persons with less education—they appeared to gain more knowledge about mental retardation than those with advanced degrees.'*

guidance and assistance in facilitating dialogue (2). Developing relationships with patients with whom communication is difficult may be even more important than doing so with a fully communicative patient (7). Moreover, the right of persons with mental retardation to be informed and make decisions about health care options is more than morally virtuous; it has become a legally enforceable civil right, which has been increasingly expanded by the courts in the past two decades (8). The passage of the Americans with Disabilities Act in 1990 has further reinforced the rights of those with disabilities to have equal access to all aspects of society's services.

There has been a general lack in the training of professionals in behaviors and attitudes that are effective in communicating with persons with mental retardation (9). The available communication enhancement strategies need to be adapted to the health care setting and integrated into training curriculums (10) in the same way that training has been provided for professionals whose patients are adults, children, the mentally ill, and the elderly (11). This observation is especially true for populations that are often stigmatized and perceived as being "undesirable" or "uncooperative" patients. Providing a learning experience in which trainees are exposed to members of these populations is important if negative attitudes and stereotypes are to be countered and positive skills are to be developed.

The educational program described in this report provides instructions concerning effective communication with persons who have mental retardation regarding the implementation of their health care regimen, and it may be used to provide an opportunity for health care providers to practice communicating with a person with a developmental disability in a health care setting. Evaluation of the program demonstrates that basic communication

skills are often not generalized to unique patient populations by trained health care professionals unless specific training is provided in regard to these unique patient populations.

### **Educational Materials**

"Making Contact: A Strategy to Train Health Care Professionals to Communicate with Adults with Mental Retardation" (12) consists of (a) a 25-page self-instructional text, (b) a 20-minute companion VHS video presentation in which health care professionals model functional methods of assessing and responding to the level of understanding of a patient with mental retardation in health care settings, and (c) instructions for developing practice opportunities for the trainees. Additional material included with the educational program consists of instructions on the use of the program and evaluation materials. Trainees generally complete their review of the materials within 45 minutes. The educational materials are available from the authors.

The text and companion video outline two areas:

- The physical and cognitive characteristics of mental retardation, including its nature, etiologies, and vocational outcomes were gathered from standard references describing mental retardation (13). This narrative emphasizes the unique capabilities of people to hold and express values and choices within the limits of their capabilities. Attitudinal factors that influence the perception and treatment of persons with mental retardation are also presented.
- The behaviors of health care providers, which enhance communication, are presented through narrative and video demonstration. These behaviors include

1. leveling: physical posturing that results in the participants having comparable eye level (14).

2. use of declarative sentence structure: Information describing the speaker's world is provided and accompanies the actions of the speaker. This guideline is suggested in "Studies of Language Interacting with Developmentally Disabled Persons and Care Providers," by B. A. Kenefick, New York State Office Mental Retardation Developmental Disabilities, Albany, 1986 (unpublished paper).

3. use of open-ended questions to avoid acquiescence: the reliability and validity of responses provided by persons with mental retardation is threatened by the tendency to acquiesce, to provide

answers which "please" the interviewer. The use of open-ended questions is a preferred strategy (15).

4. providing corrective feedback: feedback to the client following recall permits the correction of facts as well as the opportunity to reinforce participation (16).

5. removing distracting objects: communication should occur in a quiet, distraction-free area (14).

6. removing distracting individuals: communication should occur in private (15). Although persons accompanying the patient may offer important information, the patient should be the primary focus of the professional relationship.

## Methods

Evaluation was designed to assess the ability of the health care professionals to use basic communication skills when interacting with an adult with mental retardation. The design used is a pretest-posttest and a 6-week followup treatment with subjects staggered in time to control for the effect of the ongoing education or practice which subjects may have experienced independent of the education program.

**Subjects.** Volunteers were recruited to represent a broad range of health service providers who are potential consumers of the educational program. Subjects who completed the evaluations included the following groups:

- 12 nursing assistants recruited from the University of Iowa Hospitals and Clinics and from a local residential care facility who had high school educations,
- 9 nurses recruited from the University of Iowa and a residential care facility who had recently completed a bachelor of science degree in nursing,
- 12 medical students recruited from the University of Iowa College of Medicine who were in their second year of the medical training program, and
- 11 resident physicians recruited from the University of Iowa Hospitals and Clinics and the Veterans Administration Medical Center located in Iowa City who had completed a residency program in general medicine.

All persons had previously completed course work focusing on patient communication as required for entry into their respective professions. None of this course work focused specifically on communication with patients with limited cognitive or verbal skills.

Table 1. Pretest, posttest, and followup scores in communication skills of health professionals

Category	Pretest	Posttest	Followup
<i>11 medical residents</i>			
Open questions <sup>1</sup> .....	31.8	66.0	56.9
Corrective feedback <sup>1</sup> .....	43.9	37.5	52.8
Declarative sentences <sup>1</sup> .....	110.6	87.2	80.2
Leveling <sup>2</sup> .....	10	11	11
Remove distracting objects <sup>2</sup> .....	6	11	11
Remove distracting persons <sup>2</sup> .....	5	10	10
<i>12 medical students</i>			
Open questions <sup>1</sup> .....	32.3	50.1	129.4
Corrective feedback <sup>1</sup> .....	80.8	72.7	38.9
Declarative sentences <sup>1</sup> .....	143.4	105.4	45.8
Leveling <sup>2</sup> .....	11	12	12
Remove distracting objects <sup>2</sup> .....	2	12	11
Remove distracting persons <sup>2</sup> .....	9	12	12
<i>9 nurses</i>			
Open questions <sup>1</sup> .....	61.2	85.2	39.9
Corrective feedback <sup>1</sup> .....	44.2	36.3	22.1
Declarative sentences <sup>1</sup> .....	103.1	71.3	88.7
Leveling <sup>2</sup> .....	9	9	9
Remove distracting objects <sup>2</sup> .....	3	9	9
Remove distracting persons <sup>2</sup> .....	2	8	5
<i>12 nursing assistants</i>			
Open questions <sup>1</sup> .....	30.7	52.1	36.3
Corrective feedback <sup>1</sup> .....	14.5	58.5	28.0
Declarative sentences <sup>1</sup> .....	58.4	49.0	63.5
Leveling <sup>2</sup> .....	12	12	3
Remove distracting objects <sup>2</sup> .....	3	10	12
Remove distracting persons <sup>2</sup> .....	4	12	12

<sup>1</sup> Mean number of seconds when each skill was used.

<sup>2</sup> Total number of role plays when behavior occurred.

**Design.** The training procedure was as follows: subjects were pretested via a videotaped role play with a patient with mental retardation; subjects read the manual and viewed the video components of the educational material; subjects were posttested via a second videotaped role play with a patient with mental retardation; and subjects completed a posttest for retention of knowledge of communication skills.

Subjects were paired within their professional group and the members of each pair randomly assigned to one of two groups. The communication skills of the first group were evaluated immediately before and then 1 week after they had read the manual and viewed the video. The skills of the members of the second group were evaluated in the same sequence as those of the first group, but the first role play evaluation was delayed so that it coincided in time with the second evaluation of the paired member of group one. Thus, it could be determined if there were other educational events which may have caused an increase in communication skills.

tion skills independent of the educational materials and role plays. The skills of both groups were evaluated for a third time after 6 weeks to assess the subjects' retention of the communication skills.

**Measures.** To assess the health professionals' ability to use the desired communication skills, they were videotaped in a model health care examination room while performing the pretest, posttest, and followup health care role plays (that is, examining and caring for a minor burn) with an adult patient who simulated having a moderate degree of mental retardation. These adults with moderate mental retardation were verbal, capable of following two-part instructions, and were all employed and residing in community-based programs. The subject-trainees also completed a short quiz about the educational material immediately following the pre and posttest role plays. The trainees' use of the six communication behaviors that are the focus of the educational materials were later observed by one of three research assistants who were blind to the evaluation procedure; they had been trained to identify reliably the six behaviors to a 85 percent occurrence agreement criteria. These observers recorded, in real time on a Datamyte 1000 hand-held data collector, codes reflecting the presence of the six communication behaviors which have been operationally defined for observation and coding purposes.

We constructed and a research associate scored a 20-item quiz that required subjects to recall specific information about the basic characteristics of mental retardation, which had been presented in the educational materials.

## Results

**Reliability of the observers.** The three observers were trained before beginning observation of the videotaped role plays to identify reliably the six communication behaviors to a 85 percent criteria. To ensure that the behaviors were continuously and reliably observed during the data collection process, 25 videotaped role plays (20 percent of the total number of videotaped role plays) were reviewed by all three observers. The observers were not aware which videotaped role plays were used for reliability testing. Because of the high accuracy of the Datamyte recording system, it was not expected that observers would agree on both the communication behavior and the exact time (to the second) when each behavior occurred. Rather, reliability on occurrence was determined by sequential analysis of

the recorded behaviors. Therefore, agreement occurred when the observers agreed upon the sequence of behaviors and the behavior was recorded by all three observers within the same 5-second interval (that is, the observers agreed that leveling preceded an open-ended question followed by a response from the confederate, and the observers were within 5 seconds of each other in recording those events). Occurrence agreement among observers ranged from 76 percent (use of declarative sentences) to 100 percent (leveling, removing distracting persons) suggesting an acceptable level of observer scoring consistency.

**Subjects' use of the communication skills.** The data were examined to determine if members of the four professional groups benefited equally from the communications training program. Resident physicians, medical students, and nursing assistants increased their use of open-ended questions (*t*-test,  $P < .05$ ) and corrective feedback (*t*-test,  $P < .05$ ) while decreasing the amount of time they spent using declarative sentences (*t*-test,  $P < .05$ ), as can be seen in table 1. All professional groups increased the use of leveling, removing distracting objects, and removing distracting persons. The amount of time spent providing practice and corrective feedback increased following training, but the amount of time decreased at followup. This may have been due to an improvement in the simulated patients' abilities to perform the desired behaviors over time. A one-way analysis of variance employed to compare the number of seconds when the skills were used and the open-ended questions, corrective feedback, and declarative sentences that were used indicated that there were no effects by profession on posttest scores that were significant at the  $P < .10$  level.

Data from the knowledge quiz indicated that the nursing assistants benefited most from the educational materials (table 2). This group increased the number of questions answered correctly from pretest (68 percent correct) to posttest (76 percent correct), and a *t*-test for related means indicates this increase is significant at the  $P > .05$  level. Members of the other professional groups, groups who may have had collegiate level instruction about mental retardation, did not raise their scores significantly.

The final analysis focused upon differences between the two paired groups—the 22 subjects who initially received the educational materials and the 22 subjects who served as controls for the evaluation. Initial analysis indicated persons who served

as controls did not improve their performance as they waited to receive the educational materials. The members of the control group did improve their use of the communication skills following their study of the educational materials. A one-way analysis of variance employed to compare the number of seconds when the skills were used and the open-ended questions, corrective feedback, and declarative sentences used indicated that there were no group differences on posttest scores. Similarly, there were no group differences in the number of role plays in which leveling, removing distracting people, and removing distracting objects occurred. Data from the quiz indicated that there were no differences between group members in their ability to increase the percent of questions answered correctly.

## Discussion

The results of the evaluation process indicated that despite previous interpersonal communication training within their respective professional programs, the health care professionals, regardless of professional status, often did not use basic communication skills before reviewing the educational materials. Participants often conducted interviews with the examination room door open into a public hallway, and their communication primarily consisted of directive instructions with a minimal amount of patient interaction. It is unclear if the health care professionals who were the subjects of this study would perform similarly if the simulated patient had not had mental retardation.

The short presentation of the communication skills, within the context of the health care setting with video examples of health care workers effectively using the skills to communicate with actual persons with mental retardation, was effective in changing some of the communication behaviors used by the participants. The effectiveness of the educational materials on improving communication skills was not different for health care professionals with advanced educational degrees than for persons with less education—they appeared to gain more knowledge about mental retardation than the persons with advanced degrees.

Members of health care groups from all educational backgrounds were successful at incorporating the contents of the program into their interactions with the simulated patients with mental retardation. Informal feedback from all participants in the training program indicated that they felt they would more likely use the techniques with all

Table 2. Health professionals' knowledge of mental retardation, in percentages

Health professionals	Correct answers	
	Pretest	Posttest
Medical residents .....	85	85
Medical students .....	87	88
Nurses .....	80	83
Nursing assistants.....	68	76

patients, that the persons with mental retardation were "more able" than they had previously assumed, and that such role play experiences should be combined with their clinical training.

The degree to which the educational material altered attitudes is unclear and difficult to measure. Such assessment of attitudes toward disability groups is often limited to written surveys, which have revealed mixed results (9). Data that documents changes in activities (for example, increasing access to health care, working with disabled patients) are more difficult to obtain, but are a more robust indicator of positive attitude change. Health care professionals, in general, do profess positive regard for persons with disabilities and try to treat them as they would nondisabled patients. Yet, many professionals do not afford persons with mental retardation the same privacy and information that they might accord nondisabled patients, often because of limited skills and training in dealing with those with cognitive disabilities.

This study suggests that health care professionals need educational opportunities in which they can learn and practice techniques for use with special populations. It cannot be expected that persons will generalize the communication skills that they have learned with "normal" adult patients and adapt them to meet the needs of these special patient populations. This may be especially true for patient populations for whom it is generally and inaccurately perceived that they cannot provide accurate information nor follow directions.

When patient populations are stigmatized, it is incumbent for educators to provide additional training to their students to help them better serve these persons by identifying techniques to overcome stigmatizing barriers, such as the barriers created by difficulties in communication. Through positive learning experiences, negative stereotypes, where present, can be dispelled and more positive attitudes towards persons with mental retardation developed. As the program we present demonstrates, opening communication requires a minimum investment of time and effort.

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## Financial and Time Costs to Parents of Severely Disabled Children

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## Synopsis.....

*This paper considers the financial burden of parents caring for severely disabled children. A model to predict parents' out-of-pocket expenses and caregiving time demands is described.*

*Discriminant analysis correctly classified high and low group membership for out-of-pocket expenses and caregiving time at 72 percent and 77 percent, respectively. Expected rates were 50 percent. Time spent caregiving was the best predictor for out-of-pocket expenses, and out-of-pocket expenses was the best predictor of caregiving time.*

*A need-based approach for the distribution of resources that recognizes and adjusts for caregiving time and out-of-pocket costs is recommended.*

**I**N THE UNITED STATES, an estimated 10-15 percent of all children have a chronic illness, and 1-2 percent have a severe chronic illness (1). Because the care of these children is often demanding and expensive, many families face financial difficulties. For example, Newacheck and McManus (2) re-

ported that children limited in their activities use more medical services than other children, especially hospital-based services and nonphysician health services, and that out-of-pocket expenses were two to three times higher. They also report that there is an uneven distribution of financial